Parkinson's Disease Version 2.0 NINDS CDE Project
Epidemiology and Environment Subgroup

The Epidemiology and Environment Subgroup for Parkinson's Disease (PD) Common Data Elements focused on the assessment of environmental exposures associated with PD risk, disease progression and other disease characteristics. This includes the assessment of risk across populations that may vary by disease rates, geography, socioeconomic conditions, and culture. The subgroup selected existing instruments that have been validated when available and adaptable to international research. In some cases, more than one instrument was suggested depending on the required depth of exposure measurement. When these criteria cannot be met, non-validated but reliable instruments were chosen or gaps were identified, if none exist. Other methods of obtaining environmental data, through record linkage to routine administrative or surveillance data were discussed with exemplars though data will depend on local availability. The ultimate goal is to have common data elements that can be utilized for observational and experimental designs, administered in a standardized way and compared between different studies to examine generalizability and heterogeneity of PD etiology around the globe.

The subgroup began reviewing common data elements for environmental exposures by selecting broad categories of exposure relevant to PD. The preference was to select existing instruments from the PD v1.0 Project that were validated and expand the development of CDEs when the criteria could not be met. A summary table of the recommendations is included below.

The subgroup reviewed differential application to subpopulations within PD and included the assessment of risk across populations that may vary by disease rates, geography, socioeconomic conditions, and culture.

The Epidemiology and Environment CDEs are aligned with the Movement Disorder Society standards and PhenX Toolkit Social Determinants of Health protocols.

The subgroup determined that the issues encountered when developing the CDE standards are not unique to PD, but subjects with moderate/advanced disease may have cognitive issues or Parkinson's Disease dementia which will adversely affect recall of past events. In addition, they may have difficulties completing paper-based forms depending on severity of tremor and other PD symptoms. Advancing motor and non-motor symptoms limit the ability to physically obtain exposure data that may be relevant for more severe or aggressive phenotypes of the disease.

The subgroup found that most of the research needs about measuring life course exposures are generic and not specific to PD epidemiology. For example, the validity of past reported exposures and how one can improve this in the absence of objective records or semi-objective measures of exposures e.g., job exposure matrix for neurotoxic exposures. Additionally, standard assessments found in the other areas of aging might be important for understanding and comparing PD to other geriatric syndromes and diseases of aging, (e.g., those that focus function, ability, and frailty) rather than symptom burden.

Summary of Recommendations

Subdomain	Instrument/CRF/Guidance Document Name	Classification
Epidemiology/Environmental History	Food Frequency Questionnaire (FFQ)	Supplemental
	History of Early Exposure	Supplemental
	Infection History	Supplemental
	Non-Prescribed Drug Use Questionnaire	Supplemental
	Nurses' Health Study Questionnaire (NHQ)	Supplemental
	Ohio State University TBI Identification Method Short Form	Supplemental
	PhenX Toolkit Social Determinants of Health Guidance Document	Not applicable
	Risk Factor Questionnaire (RFQ) – NSAIDS and Calcium Channel Blockers (CCB)	Supplemental
	Risk Factor Questionnaire (RFQ) – Occupation and Employment Status	Supplemental – Highly Recommended
	Risk Factor Questionnaire (RFQ) – Physical Activity and Sleep	Supplemental
	Risk Factor Questionnaire (RFQ) – Residential History	Supplemental
	Risk Factor Questionnaire (RFQ) – Toxicants	Supplemental
	Risk Factor Questionnaire (RFQ-U) – Height and Weight	Supplemental
	Risk Factor Questionnaire (RFQ-U) – Pesticides (Home)	Supplemental
	Risk Factor Questionnaire (RFQ-U) – Pesticides (Work)	Supplemental
	Risk Factor Questionnaire (RFQ-U) – Smoking and Tobacco	Supplemental
	Secondhand Smoke Microenvironment Questionnaire	Supplemental